

Assessing scientific engagement of individuals with lived experience of intellectual and developmental disabilities among the IDDRC network

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Introduction:

People with lived experience of disability (PWLE) remain underrepresented in science and research. Intellectual and Developmental Disability Research Centers (IDDRCs) aim to promote interdisciplinary and translational research. However, limited evidence exists on how these centers engage PWLE in meaningful ways.

Methods:

A cross-sectional mixed-methods survey was developed and distributed electronically to IDDRC directors to assess engagement practices with PWLE, including conceptualizations of engagement, perceived effectiveness, and barriers to inclusion.

Results:

Ten responses were received, with 8 reporting engagement with PWLE, 1 reporting no engagement, and 1 unsure. Quantitative data were analyzed descriptively, and qualitative responses were examined using a structured thematic approach, with data organized into domains and coded by valence (positive, negative, neutral, or mixed). Results indicated that PWLE were most commonly engaged in providing input, collaborating on research, and receiving compensation, but were less frequently involved in co-authorship and decision-making roles. Thematic findings showed that engagement was most prominent in Governance & Structures and Partnerships & Community, with largely positive and neutral perceptions, whereas Resources & Compensation and Research Collaboration & Authorship reflected more negative experiences. Communication & Dissemination was primarily described in neutral terms.

Conclusion:

Overall, findings suggest that while IDDRCs demonstrate meaningful engagement with PWLE in several domains, opportunities remain to expand inclusion in higher-level research roles and address structural barriers, particularly related to compensation and collaboration.